

WALK OUR PATHS

INSPIRATIONAL STORIES
OF INDIVIDUALS WITH AN
ACQUIRED BRAIN INJURY



HEADWAY

Brain Injury Services & Support



Cover Credit: **Chris Delaney**



“The butterfly is a symbol of transformation and change. It’s emerging from the water; this represents the physical and spiritual journey of the person with an Acquired Brain Injury towards his or her new life.

“The shades of blue in the sky are for calm and spirituality, the orange and yellow of the butterfly are for happiness and warmth”

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About Headway

An Acquired Brain Injury is usually a sudden and unexpected event that could happen to anyone. It can be caused by a stroke, a bleed on the brain, an infection, a tumour, a fall or a traffic accident, for example.

There are approximately 30,000 people in Ireland living with an Acquired Brain Injury and it is estimated that every year between 9,000 and 11,000 people sustain a Traumatic Brain Injury in Ireland.

Headway is a not-for-profit organisation that provides rehabilitation services for people living with Brain Injuries. It was founded in 1985 and is accredited internationally by CARF (Commission for Accreditation of Rehabilitation Facilities). Headway's aim is to help people with Acquired Brain Injuries to rebuild their lives. Headway helps individuals to make the most of their potential, improve their quality of life and increase their level of independence. Every Brain Injury is unique; therefore, all Headway services are tailored to each individual, based on their needs and their goals.

An Acquired Brain Injury does not just happen to one person in isolation – it can often have a significant and devastating impact on their family as well. Therefore, Headway helps and supports family members as well as the individual affected by the Brain Injury.

Headway offers rehabilitation services in Dublin, Limerick, Kerry, Carlow and Cork. It provides:

- Information and Support
- Community Re-Integration
- Vocational Support
- Support Groups
- Counselling and Psychotherapy
- Neuropsychological Rehabilitation

We help Fundraising events throughout the year; please check our Facebook page (Headway Ireland) for more info.

HEADWAY
Brain Injury Services & Support

Introduction

I have been really delighted to be involved with creating our book, our story.

There are so many people who have had been impacted by Acquired Brain Injuries - young, middle aged or old, this can happen at any time - and sadly their lives can be turned upside down, often within the scary blink of an eye. Once, they had their futures sitting in the palm of their hands, everything ahead of them; plans made, hopes grasped. And then they're suddenly struck down, with no alarm or ringing bells, just the stark reality that everything has now "changed, changed utterly, a terrible beauty is born" (W.B. Yeats).

So this book tells their true tale, people like us, survivors. Their pain, their struggle, their hopefulness, feeling that they have become the unwanted, dropped onto the rubble skip of life.

But some, they said "No. I will not fall down. I will not just disappear." Bridges can be rebuilt; new routes can find a way; new things can be created from nothing. These barriers and barricades can be broken down; they are not fully used, they can evolve and even little apples can blossom and search for a kinder, better future.

Sometimes I believe I see myself as 'The Glimmer People' but unfortunately some others might think that we are now less bright. But they are so wrong and we do matter. For we do have a voice and an opportunity to be heard, to be listened and understood.

The contributors to this book have created wonderful images and pictures of stories of hope, conjured up from the ashes by these 'Lovers, Painters, Poets and so much more' and they still continue and are connected.

So this book is their story, proof that they are more than just survivors. They have had to change, to accept and acknowledge the things that they can't control, but more importantly, they have shown that there is a new and different point of view and they are more than happy to share, openly, to kindle a real awareness of Acquired Brain Injuries, to show that there is life after all.

Derek Cummins

**“ As individuals we
are strong but travelling
together, we are a force to
be reckoned with! ”**

- DEIRDRE O'BRIEN -

Someone Else's Body?

by **Deirdre O'Brien**

It was the last Friday in April, three years ago, a beautiful, bright sunny day. That morning, I got my nails done, choosing my favourite colour, purple. It matched the trim on my uniform for the busy week ahead in the Convention Centre, where I was working as a host.

That afternoon, I worked in the cloakroom as the delegates arrived to register. I remember being really tired that day and my feet were very sore as I made my way from the train station back home.

I set my clock for 5am the following morning as we had an early start for first official day of the week-long conference. When I woke up, Willie, my husband, said he didn't feel well and was going to walk to our GP as he was too ill to drive. I was a bit worried, so I contacted work to let them know I had a problem and would be in later in the day. I then started tidying the kitchen and put on a wash, while waiting for Willie's doctor's appointment.

Without any warning, a very strange feeling came over me. I told Willie I wasn't feeling too good and we figured that we must both have caught a bug; he set off to his appointment. After a few minutes, my daughter Emma called down from upstairs asking was I okay. I said I thought I was going to faint and she came running down to see if I needed help.

Emma asked me to look at her, which I did. Then she said, "Smile at me, Mam." I tried...

"I'm sorry Mam but I think you're having a stroke," she said. "I'm calling an ambulance!"

It was as if a bolt of lightning hit our house that day, coming through our roof, hitting my left side and changing our lives!

I tried to walk to the other side of the room, ending up on the floor! Emma attempted to lift me but I stopped her. She covered me with a blanket and propped me up with cushions. The person who took the 999 call told her to try to keep me conscious and we chatted about seedlings I had bought her from Lidl and how she would transplant them. Kate, my youngest daughter, who was teaching in a local school, arrived and then the ambulance was there.

The guys were so good and so reassuring. They immediately took control. Emma explained what exactly had happened.

“Don’t worry, we’re going to help you”

Me: “Oh I’m so sorry, I just can’t stop shaking and chattering my teeth”

“We’re giving you some oxygen that will help... Damn this blood pressure monitor must be broken; I’ve never seen such a high reading. This could not be right! It is; I took it twice or three times. Oxygen blood levels very low. Can’t get a reading at all.”

He smiles at me, “Oh that’ll be the nail varnish block. You have your nails done”

Me: “Yes. They match my uniform perfectly””

Then the siren’s on, the girls jump in, and we’re off to Connolly Hospital. Part two of my life has started and I’m sobbing but blissfully unaware of what lies ahead!!



'Someone Else's Body'

It's like you're in someone else's body,
And you want to shout it's me; I'm in here.
I just look and act a bit different,
But it's just me, still the same inside.
Like your mind still goes at the same fast pace it used to,
But it just can't get your body to move at the same speed,
A bit like trying to cycle a bike with the chain broken,
You have to push very hard,
But you're not getting very far.
It's so frustrating!
You try to explain
But the words sound wrong,
And your voice is not the same either,
Like a stranger has given you their voice,
And it sounds so croaky and flat.
You're so tired with all this extra effort.
Is it worth the endless trying? People,
Probably fed up with how slow,
How awkward, how clumsy I now look!!

And so it was that on the first day of May 2018 I found myself on a bed in Connolly Hospital. The second part of my journey was unfolding and I was lying there wondering if I should ask if I would still be okay to fly to New York the following weekend!

My life had completely changed, but this second half strangely became the most amazing, uplifting and funny time of my life!

No, I never expected to suffer a stroke and the inevitable brain damage it leaves behind. But neither did I expect to meet dozens of the nicest people in the world. I don't exaggerate when I say that most of my time in Connolly, I lay or sat at my bed thinking how lucky I was to have so many great people around me. Yes, there were tears; the stroke team said that I was sobbing when they brought me in. There was more crying on the day in the stroke ward when it dawned on me how things would change.

"Hang on" I actually said out loud as the penny dropped. "If I can't walk, how can I drive? How am I going to dance and do my Zumba class?"

More tears and more tissues. Where would it stop?

There and then, I decided whatever else happened, I would dance again and I would drive again. But first things first, I will first try to walk to the loo (needs must). My new life had begun and my journey had started.

I had some astonishing thoughts during the following weeks and months. There were even times I thought how lucky I was to have had a stroke. It was like a door had opened to a whole new world full of the most fabulous people, who, although they were adapting to a new life themselves, were always ready with a helping hand or kind word when it was needed.

I have so many wonderful memories of my time in Connolly Hospital, like the day Nicola, one of my physios, tricked me so that I moved my left arm for the first time after the stroke. Or the evening the girls came in to help me into the shower and Kate dressed head-to-toe in protective gear, definitely not her best look. I vividly remember Anne, who partnered up with me for physio, standing on her crutches saying she wanted me and her

to be just like normal people. "But Anne, we are normal people," I said, but I knew what she meant! I cried again when I was leaving Connolly and all the wonderful friends I had made there.

There were more tears and more tissues when two months later, I got a call to report to the National Rehabilitation Hospital (NRH) in Dun Laoghaire. There are not enough words or hours in the day to relate the amazing world I fell into the day I was admitted into this incredible facility for physio and therapy. If there is a heaven and a place where miracles occur, then it's run by the HSE and located on the south side of Dublin in the NRH.

Ten weeks after my stroke, I was back home, wondering what had happened and terrified to think about whether I would ever be 'me' again.

The next step on my journey may not have been so dramatic or traumatic, but it felt like someone taking a huge pot of ointment and covering the next six months in a soothing balm. It began the day that Michelle called from Headway and I took the next step on my journey back to my life.

I am hoping by now that I have caught up with you on your journey, that you have also taken this first step. We have reached the crossroads where our journeys intersect and I'm hoping we will travel this part together. It was never going to be a smooth road that we travelled, but we knew that.

We don't know when or where this journey will end for either of us but one thing I do know is that my journey this far has been made a little easier and more bearable because of the people I have met along the way. People like me and you, the "normal people" who have shown me that life can be worth living again. As individuals we are strong, but travelling together we are a force to be reckoned with!

**“ My jigsaw puzzle is
nearing completion and
I’m happy with who I am
and where I am in life ”**

- UNA MARY ELLIOTT -

I Cannot Really Believe

by **Una Mary Elliott**

Life can change in a second to something you never realised it would be, something you would not wish or dream or drive towards: but it happens.

I worked in the financial sector within a large organisation and in 2017, after 38 years, the opportunity came to take redundancy. Whilst I was a bit anxious about making the decision, I could feel I was doing the right thing in life, so I started making great plans. I was going to focus more on my creative side, take some time out and set up my own little business where I could control and decide what would happen. My darling husband Richard was behind me all the way. We both saw the benefits these changes would bring to our lives.

After doing some research, I decided to take a Diploma Course in floristry in a very well-established school in The Netherlands, the country of flowers, with the biggest flower market in the world. I looked forward to this next chapter in my life with great enthusiasm. I was going to Aalsmeer, a few kilometres outside of Amsterdam, the heart of floristry, where I would spend eight weeks before returning home with the world as my oyster.

I left for the Netherlands in August 2017 and just plunged in straight away. I loved what I was doing, the place I was in, the people I met and everything about this new trade I was learning. It was tough and took a lot of time; there was homework every night, as well as weekend projects and a host of horticultural names to learn. However, I was totally enthralled and interested in what I was doing, meeting and socialising with people from all over the world. My life was just becoming so liberating that I was in seventh Heaven. My dearest mother used to call me a social butterfly, and I really was living up to that name in Aalsmeer.

The hardest part was leaving my husband, my family and friends behind me, but I'd organised for some weekend visits and trips around Amsterdam, a place I was beginning to love again after many years.

Richard visited on the weekend of September 15. He had organised a beautiful boutique hotel in The Hague (Den Haag) and we were going to enjoy the lifestyle there, to see some beautiful art galleries and perhaps take a trip out to Delft and along the coastline.

Little did I realise that on the Sunday morning, September 17, my life would change.

I woke around 8am and I got up to make tea and coffee for myself and Richard, which we'd have sitting up in bed as we decided what to do for the day. Getting out of bed is the last thing I remember for seven days.

I had collapsed due to low blood pressure; that's all that could be established when I returned to Ireland. I hit the floor, burst my eardrum, fractured my skull in three places, damaged the nerves on the right-hand side of my brain, ultimately ending up with Brain Damage, but was lucky as my burst eardrum allowed the blood to flow out, thus reducing my Acquired Brain Injury.

The outcome was devastating. I could not walk properly; my balance was gone. I could not blink or close my right eye, not could I create tears, and my vision on this side was severely impaired. I could only eat small amounts of pureed food and drink via a straw, as I could not open my mouth, and my speech was difficult. My hearing on my right-hand side was also impacted and I had a very deep ear infection. I could not understand the words on a page or even understand what was happening around me.

I remained in The Netherlands for two weeks before flying home. I found this difficult, but my doctor, the team in Beaumont Hospital and the National Rehabilitation Hospital were just fantastic, both in these initial stages and over the months to come.



He next two years-plus of my life were built around medical appointments, operations and physiotherapy. I went through balance physiotherapy, neuro physiotherapy, cardiac assessment, neurology assessment, speech & language therapy, ENT for my burst eardrum. Through my speech & language therapist, I heard about Headway; she assisted me in completing the form and the rest is history.

Initially, I was full of fear and anxiety. I did not know what had happened to me and why. Would I ever be able to go out again? What did people think of me when they saw me? I had plenty of stares and strange looks, but others would realise there was something about me and they gave me space.

I felt that I was no good anymore, that I could not do anything correctly. I had always given everything my best, with great determination, and here I was now with nothing to give, or at least that was how I felt. I was putting on a brave face, but deep down inside I was melting: my hopes and dreams had flown away.

My family and my closest friends were naturally very upset but also very supportive to me and Richard; they most definitely helped us through some very dark and deeply sad times, most of which were spent doing my exercises, attending my medical appointments and then wondering what would happen to me.

Eventually my natural determination started to click in and motivate me to do the very best I could, however I could do it. Perhaps it was going to be slightly different, but I would certainly do it to my very best.

What was I thinking? I would still be able to do things in life, but they might be different or even new.

My initial contact with Headway was a little frightening; I was still attending medical appointments while trying to see myself as a person who could still keep going onwards and upwards. It is a part of my recovery, I told myself, reminding myself to keep going. There were tears; in fact there was total upset, but something in my brain clicked in and told me to take each step lightly and that I'd be OK.



The crew in Headway were fantastic, giving me support and time, with a lot of encouragement and great respect. They provided me with superb facilities, such as assessment, compassion therapy and counselling, and it felt like being enveloped in a comfort blanket. They helped me to walk my path, provided me with a feeling of security and love. They also helped me to realise that there was a way forward; I was still able to complete what I would like to do by accepting that it might just be different or something I had not thought of before.

I'm back to doing flowers, my gardening and daily life activities. Where Headway are concerned, I've reached some higher achievements, as I am now completing artworks that I never thought I could and participating in a choir, a social group and fundraising activities.

It has made me re-evaluate my life and see what is most important to me, where I am able to enjoy the things and people who surround me. My jigsaw puzzle is nearing completion and I'm happy and content with who I am and where I am in life. It's just wonderful to feel like this.

**“ It [my rehabilitation] was
a long road, but Headway
made it shorter ”**

- MARTIN PARKER -

Perhaps

by Martin Parker

After two strokes and a few heart attacks I was so confused, Headway explained what had happened to me in relation to my Acquired Brain Injury and what to expect. It was a long road, but Headway made it shorter.

'Perhaps'

I walk the streets,
The whispers in my head,
Asking Why?
Why don't I stay in bed ?
I sit in the dark,
But I hear the questions,
But not the answers,
I stare at the light so far way,
I wonder maybe,
Maybe one day with help, with Headway,
I can step into light and perhaps,
Perhaps find my way?



**“ The day of my accident
I saw two robins sitting
outside my kitchen
window and I believe
there were there to
protect me and help me
survive my accident ”**

- GILLIAN O'LEARY -

Running Away Without Leaving Home

by Gillian O'Leary

Hi, my name is Gillian O'Leary.

I suffered traumatic and Acquired Brain Injuries from a stroke and brain haemorrhage. On my last week in hospital, a lady came around with art supplies and asked if I would like to do some painting and I said yes. I continued the art at home and have recently started art lessons. This is my first painting I completed in art class, which has a special meaning to me; the day of my accident I saw two robins sitting outside my kitchen window and I believe they were there to protect me and help me survive my accident. Through post-traumatic stress after the accident, I found art a really creative and helpful way to express myself and forget about my thoughts for a while. Art is the only way to run away without leaving home!



**“ Swimming upstream
is a metaphor for moving
forward in life (after an
Acquired Brain Injury),
challenging the medical
and personal side effects,
swimming through the
realities of living with an
Acquired Brain Injury ”**

- DAVID O'HARA -

Upstream

by David O'Hara

This is an abstract poem based on salt water Atlantic salmon swimming upstream through fresh water for reproduction - a daunting task. It is used as a metaphor to describe moving forward in life, challenging the medical and personal side effects, swimming through the realities of living with an Acquired Brain Injury.

'Upstream'

Crashing waves make predictable behaviour, once traversed by an unfortunate few

**From the Atlantic to a slanted fresh start - a fresh upstream, only embraced by the jagged rocks and those around who are more versed
No half dull hook, opportunities thrown, as a more than welcomed innominate saviour**

Beginning or the end, strongly wagging tail or salted wounds – who's there when the upstream is opposite?

**No description, no composite flow,
candidly left below with only self-imposed synonyms of menace
Salt to fresh to the consensus of a mindless crevice;
replenish, full circle, what was before.**

**Lips bound; upstream now attainable by tooth and nail,
tracking post and nagging email –
fins and gills spend too much time speaking and spitting ash.
It's time for a more fitting string to be reeled in.**

It's a tiring challenge of those who challenge so lick those wounds and call it a new-found fetish, an irrational reasoning to hash a salty stomping ground

Prompt change. Evolve. Withdraw from the current and relearn those steps taken. Recant the swamp mentality and wear your own river of redistribution.

**“ My fellow clients in
Headway have helped and
guided me when I needed it.
Ye are all very special and
I shall never forget: we all
suck the same air ”**

- CLENTON DUFF -

Realising I was not alone made all the difference

by **Clenton Duff**

In mid-June 2017, I sustained an Acquired Brain Injury (aneurysm) that required surgery in Beaumont Hospital – I'd like to thank all the staff there for taking excellent care of me.

After three months, I returned to work thinking I was okay; I was not. I struggled doing what I did before injury, and many other things seemed out of reach.

I presented to my GP, who recommended Headway. In October 2018, I started in Headway, taking part in Compassion Therapy Group. I was not alone anymore; we all shared the same injuries. The group covered so much. I felt safe, realising that change was not so bad after all.

Moving on, I have taken part in so many activities, group sessions, outings, courses, social groups, and learned the art of mindfulness, all through Headway. All the staff are so committed, understanding, and go beyond what I thought was possible; for that I am eternally grateful.

Let me not forget my friends, peers, fellow clients in Headway, who have helped and guided me when I needed it. Ye are all very special and I shall never forget: we all suck the same air.

As of now, November 2021, I am so much better.

'The Chair'

I enter his demesne

Take place in queue

My turn

I land in chair

Raised to his height not mine.

Razor in hand he motors on

We break into banter, chit chat etc

That V.A.R. bleeden wrecking the game, never a goal.

Leo a gangster but clever, and so on.

Where you at it? he asks. Site round the corner, money's good; trying get few quid together for insurance and tyres for car.

After some time he reaches for mirror, takes it east, south, north and west. How's that sir?

Mmm.....

And where you working? says I.





**“ The Art group helped
me to reawaken my
creative side and gave
me a purpose in life,
something to move
forward with ”**

- CHRISTOPHER DELANEY -

The Snow Flake

By Christopher Delaney

After my diagnosis I found that I was slowly shutting myself off from the world. It took a while for me to realize that I needed help. This help came in the form of Headway and its Art group. The Art group helped me to reawaken my creative side and gave me a purpose in life, something to move forward with.

The Snow Flake

Crystallising forming
Floating down
Glittering, sparkling
Like jewels in a crown
Softly falling
Falling down
Softly falling to the ground



**“ It’s not easy being
a Brain Injury survivor
but I do the best I can
with what I have and
that’s all anybody
can do. ”**

- GARY KEARNEY -

From the Depths of Despair to a Career in the Media

by Gary Kearney, Brain Injury survivor

(Viva Vox, 103.3 Dublin City FM)

I was drugged and assaulted on March 1, 2009, and sustained several Traumatic Brain Injuries. I was taken to the Mater Hospital, where I was eventually put in a High Dependency Ward to receive palliative care. There was nothing anybody could do for me; my family were told if I survived, I would be severely disabled, both mentally and physically. This, like everything about that time, I found out much later.

My memory only provides snapshots: waking up in the Mater's A&E department on a bidet chair wondering what the hell happened me; trying to reach for a cup of water and failing; waking up in a ward with the headache of all headaches and realising this is bad and I am in trouble.

I did a safety check: can move my feet so there's no spinal damage; can speak; can I hear? I seemed to be deaf in my left ear and was seeing double. Trying to sit up was a very bad idea. But at least I was alive; that was a definite win.

That has been my attitude for a lot of my recovery. Not all of it, however. I have been down into the places only survivors know about: the depression, the anger, the frustration, the pity parties, the highs, and lows we all have. The bad brain days, brain fog, confusion, exhaustion, the whole lot of it. All of this can be in one day. Brain Injury survival is never boring; you never know what is going to happen next.

I had a life, but looking back at it, it was not one I was happy in at all. It was a mess, and I was a mess. But it was mine. Suddenly it was changed, and I had no idea of where or what my life was going to be. Nor had anybody else.

My consultant told me this and I have never forgotten it: "We know more about the dark side of the moon than we do about the human brain."

So this was to be a journey into the unknown with no clear rules or path.

In the hospital, I was taken from one professor to another to be checked out. They all wanted to meet the guy with the three major brain bleeds who was walking and talking: they called it a "miracle recovery" in one of their reports.

Almost three weeks later, I left hospital with no plan and no idea where to go to get support or rehabilitation.

I was back working in my semi-state job after three months and forced back to full hours ahead of the agreed schedule. Their chief medical officer didn't seem to understand Acquired Brain Injuries or invisible disabilities, insisting that I had no underlying medical issues, even though I was suffering from brain damage, PTSD (Post Traumatic Stress Disorder), deafness, vertigo, aphasia, depression, and anxiety, to name but a few. They tried to sack me a couple of weeks before Christmas but failed. I got a half-pension and some money which didn't last long: an Acquired Brain Injured person and their money are easily parted. I can vouch for that.

I ended up broke, in debt, and without my friends. Some of them were gone because I was a car crash of a person at times, others because they never really cared and I wasn't useful anymore.

How things have changed now. Here is how that happened.

Two years after I got my Acquired Brain Injuries, I walked into Headway and said, "Hi, I am Gary Kearney and I have Traumatic Brian Injuries. Can you help me?" That was the start of my Headway journey.

I did my initial assessment and then I was contacted by someone who became particularly important to me, Elisa O'Donovan.

With Elisa, it felt like finally, somebody listened to my problems and explained that they were real, I was not going mad and that there were people that could help me in Headway. I had found a safe space after years.

I found the unpredictability of an Acquired Brain Injury was a nightmare. I could not figure out why one day I would be great and the next in the deepest of pits of depression or my brain refused to work.

Elisa said this was normal, especially in the early part of recovery, and I needed to take an assessment for them to work out where and what my issues were. It was there I learned the Headway mantra; we all know and love.

Dr Elaine Kelly was life saver number two. Following my neuro-psychology assessment, Elaine explained what caused my issues and how I could manage them. The relief, that I wasn't going mad, was incredible.

Then she dropped the bomb on me. I had undiagnosed ADHD (Attention Deficit Hyperactivity Disorder), I had a remarkably high IQ and that I needed to manage it as well.

This did not go down well at all, but since then I have learned that Elaine is not only damn good but she's usually right too. She read me my life backwards all the way to my childhood. It was the scariest thing I have ever encountered: school, family, work, relationships, the timescales and reasons I had for what happened, the lot. Elaine explained it, gave me some material and some links and off I went down the rabbit hole of Adult ADHD and Brain Injury recovery.

Fast forward five years and I am broke, in debt and in a mess. In desperation, I ring the Headway Helpline. At a subsequent meeting I met Elaine again, who helped me to work through my issues.

I felt that I wanted to be in advocacy and so it came to be. My first event was #ISeeBeyond, an amazing campaign by Headway and Epilepsy Ireland, where I met Derek Cummins, who spoke about his journey with aphasia and taught me that I wasn't the only one with that issue. Here was a person who learned to manage it and his was so much worse than mine. He inspired me to work. It still happens but I now have the coping skills to manage it. Thanks, Derek.

Then myself and Ruth Lunnon met with the Lord Mayor of Dublin, Brendan Carr, in the Mansion House, who wanted to meet the people of Dublin with disabilities. There I came to the notice of the Disability Federation of Ireland (DFI), who invited me to work with them and sent me on a media training session. I was asked to do a 30-minute interview on Near FM for #MakeWayDublin and off I went. I did a couple of short phone interviews and that was done.

Clare Cronin, the Communications Manager of DFI, asked me would I like to present a show on 103.2 Dublin City FM called Viva Vox and the rest is history. I am now presenter, producer, and CBW (chief bottle washer) of Viva Vox, "A Disability Show With A Difference". I didn't want the show to be either a pity party or a look at super inspiring people with disabilities. It is a show about people and our issues. 180 shows later, I am still on air with and won a Community Radio Ireland/Broadcasting Authority Ireland CRAOL silver award.

I regularly appear on other stations as a spokesperson for the DFI and as a disabled activist, and was in the audience for a Pat Kenny Show on TV3 as a front row disability representative. I even spoke at super committee at Dáil Éireann as an expert witness and gave them a short version of what I am writing here today.

I appeared on Tabú on TG4 as a survivor of violent crime, discussing Acquired Brain Injury survival and found it a very strange experience, talking about what happened to me on TV.

I'm often contacted by newspapers for a comment or an interview about issues that affect the disability community. If it's not a disability I have myself, I ask another client in Headway who has this disability, and they tell me the issues.

I am also on the strategic policy committee for Dublin City Council, Transport & Traffic, where I get a chance to make sure disability access and the needs of our community are heard.

No matter where I am or who I am with, I try and promote disability inclusion and communication. I have had some successes, like the yellow mirrors on Dublin Bus and Bus Éireann, which was my first bit of lobbying. I work closely with Irish Rail and we have had some great success there as well, working with Ruth Lunnon.



I am now a member of the Headway National Advocacy Group (NAG), working to help Headway's clients with issues. For example, we helped to ensure that a set of traffic lights in Cork gave users with disabilities enough time to cross the road, we engaged in access audits in Limerick. I've essentially ended up as a Public Transport & Urban Realm activist, fighting for disability access and safety so we can go out into the public without fear.

I have so many people in Headway to thank, too many to name, from the CEO Kieran Loughran down, but they are the greatest bunch of people I have ever met, big hearted and so giving. I would not have survived and certainly not be doing what I do now without them all. The clients are a lovely, crazy family of people who understand me, as I do them.

Headway is my safe space, surrounded by people who I never have to say sorry to if my Acquired Brain Injury gets me in a muddle. As for the future, I have no idea; I have hopes, dreams and plans. There are more inequalities to fight, but after lockdown, I am giving myself a bit more time for myself, for fishing and just a bit more Gary time. With the ADHD and my Acquired Brain Injuries, I can get super focused and forget things.

There are some events I love, though, like #MakeWayDay in September and #PurpleLights on December 3. #PurpleLights is an awareness campaign and a fun way of showing support for all persons with disabilities. It's all about wearing purple or turning buildings purple; Trinity College and The Rock of Cashel in purple were a sight to see, and even featured on the RTÉ news.

I am lucky I found Headway and they are always there when I need them most. It's not easy being a survivor but I do the best I can with what I have and that's all anybody can do.

**“ The Glimmer people
are welcome to all,
Sometimes downtrodden
but never out,
As they are,
Simply Glorious ”**

- DEREK CUMMINS -

Strangers / Jacks

(thoughts and memories from Tallaght Hospital July 2013)

by Derek Cummins

Sometimes he wonders why he is caught up in the middle of a small circle. And he doesn't really know which is the bottom, the top or left or right. One thing is sure: he can't ever restart. And even if he thought he could, where would he begin ?

Anyway, in the beginning it did not make any difference; he had started his new journey with all the people who could (sometimes) help on every little step as he goes around this merry-go-round.

So he doesn't have to think too much; someone else would tell him what he actually needed to do. Eat. Wash. Drink. Shit. Sleep. Take your medications. Don't think about it. Swallow this down. Stand up. Sit down. Move your arms. Wiggle your toes. Lie down. Switch off.

Please touch his face, hold him, mind him.

And at some stage (later on) a dull light was moving; his emotions were going away from the dark. And this was not wonderful or amazing but it was a new dawn.



He was now flickering in and out of the dark – was this the ether or was this just the anaesthetic?

He did not know but he was slowly going forward – spluttering, unsure, confused and he thought he was seeing the half-light.

Simple things became a reality: he can sit up, he can move, to the chair, he can look out and see the world – a window pane of pain.

He needs to...

But he can't remember what it is called – he / it has no name, yet.

But he does know what it looks like.

Someone, a stranger, touches his hand. "Where are you going?" she asks softly.

He points, there is no point saying it loud; he knows he can't say the right words.

He is confused and he is trying so hard to begin again. She touches again his arm. "Take it easy now," she says.

He would have loved to say "feck off, stranger". But he has things to do – that he has a need ...

"What do you need/want?" says the young stranger. She reaches towards the jug. He doesn't know what this is called either – not then – but he does know he does not need this now.

"No," he says. "Piss"

She looks into his bewildered eyes and she smiles and the smile is warm.

She has seen the connect – her hand is close to him.

“This is fantastic,” she says. “You are moving toward the light.” She is excited: “This is a big step.”

And he looks at her – and he does know she is a stranger but somehow he also knows he is safe.

He looks at her and for the first time, properly, he smiles, grins and he speaks and says, “Jacks.”

'Corner Man'

Did you think you can push him in a corner?

He is not really that important -

Or is he?

Smile at him, wave at him,

But you don't actually have to look at him.

So you don't have to linger!

Focus on something else -

Anything at all is fine.

There is so much more to see!

Now he is withering away.

Each day he goes a little deeper.

Eventually he will slip aside!

And his yesterdays are silenced.

Someday they will remember

Who lived in this corner,

But he is not there anymore.

Glimmer People

She was a soldier, before she became ...
She was a corporal, proud in the 5th,
Her battalion was easier,
Than her terrified battle.

He was a fighter man,
Strong, unafraid, firm,
In London's fire brigade,
Before he was, burned out.

He was a sales director,
With a realistic target,
In his business suit with a dream a vision?
But sadly, he was switched off.

He was a young engineer,
From the British forces,
Making RAF aircraft to soar,
Before he fell from his sky.

A solicitor who once upon a time,
He was exact.
Every word, every phrase was correct,
Now his inkwell is dry.

The taxi driver, who could 'talk the talk'
Answering before the question posed,
Who knew every corner & lane,
But now he is lost.

She who was truly born to be a mother,
Safe in knowing in the bosom of a womb,
But alas she never really had her chance,
To share all her wisdom.

**Sometimes they must shriek out!
At this unfair adversity.
"This is not what we asked!"
"We are much more than this!"**

**Some wronged action, bad fate or just genes,
With brain messed up injuries,
& some in hidden disabilities,
Yes – Unsteady but surely not only,
The unwanted?**

**But they have rallied in their hope,
Of a kinder future,
It is a challenge to be changed.
But this is a fact! They do Matter.**

**They can be velvet in a chorus,
They have a right for a voice,
They need to be listened & heard,
They are lovers, painters, poets & more.**

**For these are the Glimmer people,
And they are welcome to all,
Sometimes downtrodden but never out,
As they are, Simply Glorious.**

**“ Living with an Acquired
Brain Injury pushes you to
look at your life differently.**

**You need to accept that
you are different but still
valuable, with the ability to
keep growing and learning.**

**Be kind to yourself and
stay positive ”**

- MICHELLE JOHNSTONE -

Different, But Still Valuable

by **Michelle Johnstone**

My name is Michelle Johnstone. I am 54 years old. I immigrated to Ireland from South Africa in February 2016 and suffered a brain aneurysm in December the same year. A second aneurysm was found and coiled.

It's very scary when you realise just how vulnerable the human body actually is. Especially when you have been in good health. Your recovery takes up to two years. Not long after my two years, I had a major setback after falling while shopping. This affected my anxiety and self-confidence a lot. The fear of another aneurysm is always a concern. My doctor managed to get me an appointment with Headway, and I haven't looked back since.

You have limitations, which take time to work around and work out how to achieve the best ways of completing tasks. The way you look at it shapes your future. I have always looked at everything with positivity. With the help of Headway, I am able to anchor myself when I become too anxious or overwhelmed. Dr Marcia Ward helped me find ways to become emotionally stronger in my fight to find the new Michelle, unlocking skills to achieve the very best out of my future.

Covid-19 brought its own challenges but Headway were always available to me for support and encouragement. The group therapy sessions really helped because you meet people from all walks of life and have the opportunity to see how Acquired Brain Injury affects other people. It probably was one of the most inspiring things for me to see. To be understood is incredibly uplifting and powerful.

My disability allowance was so low that I had to focus on a way to get back to work. I was filled with so much fear and anxiety, wondering if I was capable of being an asset to any business.

I was referred to the Community Employment programme, which helps people with disabilities or who have not worked for a long time to gain hands-on experience. I chose to work in retail as I was always a people person at work. I had a passion for the work St Vincent De Paul do and was lucky enough to find a position available. I just had to get through the interview. When I chatted to my support group online, I was so encouraged. I couldn't wait to tell them when I got the job.

I am most definitely not the same person I used to be, but I am able to be a part of society. We find what our strengths are and adapt. I have a great quality of life and the ability to study different things is wonderful; Ireland is an amazing country that totally supports learning.

Most importantly, I have realised how valuable we are to our children and family. I have been able to watch my daughter finish her schooling and graduate from college. She is now engaged and I was there to witness it first-hand. My son has really been very supportive, taking over cooking duties when I can't. I have been very blessed to see him succeed at work and become a man. My husband helps me with housework and anything I could need, showing great patience and empathy. These are things we usually take for granted.

Living with an Acquired Brain Injury pushes you to look at your life differently. You need to accept that you are different but still valuable, with the ability to keep growing and learning.

Be kind to yourself and stay positive.





**“ Never give up,
not for a second.**

**Stay positive, and if that
doesn't come naturally,
force and fake it! ”**

- RUTH CARROLL -

I was nine months pregnant when I was diagnosed with a brain tumour.

by Ruth Carroll

I was nine months pregnant when I was diagnosed with a brain tumour. A "C" section was scheduled straight away after diagnosis. Thankfully my beautiful little boy, Bobby, was born safe and sound. However, the day after he was born, my pregnancy hormones grew my brain tumour very quickly, which stopped the blood flow to my brain and caused me to suffer a massive stroke, which left my left side paralysed.

I am now four years post-stroke. I'm walking independently and I now care for my son independently too. I'm loving life with my husband and my son. It has taken hard work in physio and in the gym to get to this level but it's been worth every second!

It's important to find the right therapists that work well with you. The love and support from my family and friends have also helped hugely in my recovery, I've been lucky.

My top two tips are:

- 1. Never ever give up, not for one second.**
- 2. Stay positive, and if that doesn't come naturally, force and fake it!**



“ It can be hard to adjust to life with an Acquired Brain Injury but stick with it; if you put the work into rehabilitation, it makes life a little easier. There will be hard days but take them one day at a time ”

- PAT WILLIAMS -

Taking the Hard Days One at a Time

by Pat Williams

My name is Pat Williams. I am 55 years of age. I am a married family man and have lived in a rural village on the outskirts of Nenagh, County Tipperary, all my life.

The day my life changed was in May 2011. I can't remember much of what happened. I can remember the early part of the day, but the next three weeks are a blur. I was told the story afterwards of what had happened. I had suffered a ruptured aneurysm, two in fact, but it was one in particular that did the damage.

I can remember coming round and being in an ambulance from Cork to Limerick. It was a shared ambulance with a woman who I didn't know but can vividly remember the piercing sound of her voice, which went through me. I had surgery and when I recovered and came home, my wife and family found a big change in me, but they were all a fantastic support. I wouldn't have come this far without them; they are my rock.

When I came home first, it seemed as if I was just existing; there was nothing for me to do or nowhere for me to go. I would have been very social prior to my injury. My wife heard of an organisation called Headway. She made contact and arranged a meeting. My first words were "I'm not going". My wife was firm, though, and said "Yes, you are." I reluctantly came for a trial.

Fast forward 10 years and I couldn't imagine my life without Headway. I have done more than I ever thought I could.

I am involved in so much now. I engage with my local community. I attend the gym through Headway. I am on the advocacy committee. I have found my voice again and my confidence. I have completed many modules. I have learned new skills and I continue to learn new things every day.

There is also a strong social side to Headway. I have met people that I would now consider great friends. We have great fun and do lots of work, although it doesn't feel like work with the messing and craic we have too. The staff are a great inspiration, and no problem is ever too big or overlooked. I have made great progress with my recovery. I feel safe and supported and if I have a question or a concern, I know all I have to do is ask.

I have learned to adapt to my disability with the help of my wife, my family and Headway. When I think back to that time when I first came out of hospital, I could never had imagined how things would turn out. Don't get me wrong; it is still extremely difficult, and I face daily challenges. But with the circle of support I have around me, it made the journey so much better. It can be hard to adjust to life with an Acquired Brain Injury but stick with it; if you put the work into rehabilitation, it makes life a little easier. There will still be hard days but take them one day at a time.



Headway clients' Art Works



**“ Life is precious.
An Acquired Brain Injury
is no joke but it
is not the end,
just the beginning
of a new chapter ”**

- LUCY MARTIN -

Through the Rabbit Hole

by **Lucy Martin**

Many of you are familiar, I'm sure, with Lewis Carroll's story of Alice in Wonderland, who went down a rabbit hole one day: she shrank in size, doors were locked, she was without her family and could only see her home in reverse. Through the looking glass, she was shouted at, chased, threatened, sad and bewildered. She longed to be home safe and sound. This place was called Wonderland, which always puzzled me, as it seemed like a horrible scary movie. But like all good stories, Alice and her family lived happily ever after; no need for physio after the fall or psychologists after the trauma. No lasting damage, as far as we know.

I was 51 when I went down a hole like Alice. I had two adult children. I had been working in the insurance industry for 33 years and was also a part time speech and drama teacher, having tread the boards in pantomimes and plays. I had been suffering from bad headaches since my twenties, which was constantly diagnosed as vertigo. After a holiday in New York, I was quite poorly: the headaches were worse, I was unsteady on my feet and I began to drop things like cups etc. I was advised to request an MRI when I returned home, which I did.

I was diagnosed with a large brain tumour, which had wound its way around the part of my brain which manages my motor functions. Within a week, I was in hospital and after an operation which lasted 11 hours, my family were told that during the operation there was a bleed on my brain.

I was put into an induced coma and while my family anxiously sat, prayed and watched the monitors, an infection raged in my brain, causing me to hallucinate, bringing me to my own 'wonderland / scary movie'.

I was seeing the most horrible things, trying to get out of a big cavern with straw on the floor, which sat under a big old farm building. I was carrying my daughter on my back, crawling over the rough ground, desperately seeking a door or light to guide me out; it was horrendous. I was so very hot and scared. I met evil people who did horrible things. I smelled and saw extremely hot oil being poured over young children, who were being set on fire as I tried to save them. The smell of burning skin and the screaming of the children was sickening.

While this was happening in my world, it was now day 16 of my induced coma, and my partner was approached with news that the infection in my brain was not abating and there were fears that the infection could not be controlled. My brain was continuing to damage itself. Thankfully, my partner rejected the suggestion that the machine be turned off, but I've been left with a lasting fear of coming so close to death.

When I eventually was brought out of the coma after 22 days, I was exhausted, bewildered and had no understanding of what had happened. Why did I now have a nappy? Why couldn't I move or get out of bed? I was a shell of the old Lucy: bald and skinny, some memory loss, lots of confusion, pure terror and utter sadness; it seemed to puzzle everyone that I cried a lot. The psychiatric team were called in, which added to my fear, terrified that they were going to lock me up. I was stuck: stuck in hospital, stuck in bed and stuck in my mind. I underwent five further "washouts" of my brain. I felt totally trapped again and there was no psychological help at this time, only a social worker who reported back to the team on my "anxiety".

I was lost and suffering from PTSD (Post Traumatic Stress Disorder) but neither I or anyone else seemed to know that. I was labelled as 'anxious', which would work against me; the pressure was on to free up the hospital bed and move me to the National Rehabilitation Hospital (NRH) but to achieve that, I had to make the grade physically, mentally and emotionally. This totally added to the pressure I was under; effectively, I couldn't cry in front of anyone and have it reported. Feeling like I couldn't escape out of the bed to hide and cry led to some of the darkest moments of my life; I wished I could have been allowed to die in peace.

My identity was gone.

I felt sick and scared.

My son was lifting me, sitting me on the toilet.

My daughter was bathing me.

I had become a child again.

My children had become my parents.

I was trapped in a bed, petrified of the nurses and the hospital. I wanted to go home but I couldn't even remember what my home looked like and felt like I couldn't let anyone see me cry or I'd never get out of there.

My dream was that sometime in the future I might be able to get home, sit down and have a cup of tea at my own table. I was meant to feel lucky to be alive but I didn't. I contemplated how I could die but wasn't able to do anything for myself, so the only way out was to get through it, like my partner's phrase: "we are all dealt a hand of cards in this life; learn to play them well."

To cut a long story short, I eventually got to the NRH, where I was introduced to a fabulous psychologist, Dr Marcia Ward. With her support, I began to feel a little better but the turning point in my journey was when I found Headway. The neurosurgeon saved my life but it was Headway and Doctor Ward who gave me my life back. Dr Ward treated me for PTSD and gave me the most important gift: hope.

Hope that I could live again, laugh again, have my identity restored and live by the values in life that are important to me. I didn't want to be a burden to anyone. I even wanted to pay taxes and be a contributing member of society. Like Alice, I can now live happily ever after, though it took a lot of hard work from me and my family.

All the things I was told I would never do again – walk, drive, swim, look after myself - I now do with joy. Being able to shower myself is now a gift. Waking up every morning in my own bed, married to my partner, who wouldn't let go of my life; spending time with my children and grandchildren and attending to their needs; swimming with them: these are moments of complete happiness. Life is precious. An Acquired Brain Injury or stroke is no joke but it is not the end, just the beginning of a new chapter.



**“ Where there is life
there is hope and
when one door shuts,
you can always
open a window! ”**

- BRIAN HOGAN -

Walking Towards The Headway Lights

By Brian Hogan

My name is Brian Hogan. I'm a 44 year old Limerick man. In 2009, while living and working in the UK, I was involved in an unprovoked assault from which I acquired a Brain Injury and lost my sight completely. Since then, I have moved back home to Ireland and received services from the wonderful organisations Headway and Acquired Brain Injury Ireland.

I have learned how to talk again and regain my confidence. During the first Covid lockdown, rather than be consumed by depression, I set myself the challenge to walk every day. The goal was to complete the equivalent of 20 laps of Thomond Park in Limerick. My sister set up a Go Fund Me Page with help from Acquired Brain Injury Ireland staff and I raised €11,000 in total. I turned a negative into a positive and lost two stone in the process. The only smoking I do nowadays is off my heels! I must get my shoes reheelled!

Where there is life there is hope and when one door shuts, you can always open a window! Headway have been superb and turn the lights on for me every day I attend.



**“ [After my Acquired
Brain Injury] I learned
how to speak and walk again.
The rehab saved my life. ”**

- THOMAS BRADY -

I survived two car crashes

by **Thomas Brady**

I am a proud Clare man, although I was born in Limerick, and I was a keen hurler.

I was involved in two car crashes. One was in a funeral car, because the family business is undertaking. That car was in Quin after a funeral. I had too much to drink and crashed. Then the second crash was at home in Scarriff. I was nearly killed but luckily I survived. I was in rehab in Dun Laoghaire for six months. I learned how to speak and walk again. The rehab saved my life.

I was then transferred to Acquired Brain Injury Ireland House in Limerick before moving to the house in Clarecastle. I now attend services in Headway. I find the groups very educational and I like it there.



**“ Self-compassion
is the key.**

**One thing I learned
was to not be as harsh
inwardly and ask myself
what would I say to a
friend going through
the same thing?”**

- SINEAD LUCEY -

Helping Others to understand and accept my Acquired Brain Injury

by **Sinéad Lucey**

I am Sinéad, and I have an Acquired Brain Injury. Some days, that's really hard to say, but I've learned it's really important to say it. The more I say it, the more I enable my family, friends, and close ones to learn that things have changed and now circumstances are different. How I eat, drink, play, work, socialise, have taken on a new meaning.

Firstly, it was critical to understand that I didn't cause the injury; it happened to me. My lifestyle and living with chronic fatigue is not my choice, but I'm playing well with the cards I've been dealt. The initial recovery was the hardest part; when I first attended Headway, I was sullen and genuinely believed I was beyond help. Once I was able to talk through my trauma, understand my injury better and how to manage it so I could live, that allowed me to see the injury for what it is: something extra. I have extra needs, extra empathy, extra compassion, extra skills, and better awareness of what it means to be inclusive.

It's ironic that the brain is the most important part of our body and yet the least understood. If you break your leg, the bone heals but it's likely not the same as before or worse. The same goes for your brain. It's frustrating

that as a Brain Injury survivor, I'm usually accommodating everyone in my personal space, but they don't necessarily accommodate me. I'm the person with brain damage and I spend more time helping others to accept my Acquired Brain Injury instead of them helping me! So, I've learned to be okay with feeling frustrated sometimes; however, it's easier to let go of certain things to safeguard energy levels.

Self-compassion is key. One thing I learned was to not be as harsh inwardly and ask myself "what would I say to a friend going through the same thing?". That has centred me at times where I've felt like things are not normal and I "should" be doing better. I've learned to let go of "I should" and focus on "I need". I need systems to enable me to live my life better. Some of my systems include: a heavy reliance on list-making, using my Asana app on my phone for to-do items; my calendar for scheduling – if it's not in the calendar, it doesn't happen; my Amazon Alexa for routines, reminders, and timers; and building rest breaks into my work-day. I need to know I am loved and supported. And I need to feel hopeful for my future, which I do.

To build my new future, I began an advocacy page on social called The Disability Designer, where I provide education on invisible disability, because it's not widely recognised. I want to educate people living with invisible disabilities and their families on technology, products, and universal design to enable better living experiences. You can check out @The Disability Designer on Instagram, Facebook, and LinkedIn, and @disabilitydsgr on Twitter.





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The idea for this book came out of a meeting of the Headway Clients' Fundraising Team. The team were discussing ways to help individuals with an Acquired Brain Injury to adjust to their new lives. They decided to share their brave and inspirational stories in the hope of providing some help and reassurance for those who are at the beginning of their rehabilitation journey. Thank you to the clients of the Headway fundraising team; without their work, ideas and assistance, this book won't have been possible. A special thanks to Derek Cummins who put together the first draft of the book and got the ball rolling!

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Sara Sabbioni, Headway Community Rehabilitation Case Worker.

WALK OUR PATHS

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